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TITLE: Studylink: Improving Access to Clinical Research as a Prevention Method

AUTHORS: Kennedy, AO; Rosenwald, V (Clinical Directors Network, New York NY)

ISSUE: Although the NYC metropolitan area has the highest HIV case rate in the US, local clinical research sites sometimes have difficulty filling studies of new treatments. This inability to connect patients with research opportunities may be because most newly diagnosed and infected people live in the outer boroughs, and many do not receive care at the teaching hospitals and major medical centers in Manhattan, where most research is conducted. Many providers are not aware of currently enrolling studies. Because both care facilities and research facilities in New York are decentralized finding an appropriate study for a patient could be both time consuming and difficult, entailing telephone inquiries to up to 30 research sites.

SETTING: Clinical Directors Network, Inc. (CDN), a public health membership organization located in New York City, is dedicated to providing and improving community-oriented health care for poor, minority, and underserved populations and to supporting clinicians who serve these populations. CDN StudyLink is a Ryan White Title I-funded project to match potential patients with opportunities to participate in clinical research in HIV.

PROJECT: The Studylink computer contains a database of enrolling studies in the area. A patient or provider calls Studylink and gives a few details about health status and treatment history. The database sorts by entry criteria and provides a list of appropriate studies which can be faxed or mailed. CDN staff can set up screening appointments via Z-way phone calls. StudyLink insures the accuracy of the database by bringing research staff from all sites together at bi-monthly meetings. The Research Referral Coordinator conducts outreach in all 5 boroughs to community health centers and to patients to discuss treatment options and how to gain access to the benefits of clinical research through StudyLink. StudyLink aids secondary prevention efforts by providing access to investigational new drugs for patients who can not be successfully treated with available therapies, by expanding access to studies that investigate which of the first-line therapies are most effective to a larger and more diverse patient population, by facilitating the entry of recent sero-converters into studies of early or acute HIV infection, and by stepping up the pace of clinical research by shortening the time it takes to fill studies. StudyLink impacts primary prevention by reaching out to patients at counseling and testing sites. Patients who test HIV-can be referred to preventive vaccine studies or investigations comparing the efficacy of several approaches to reducing risk behaviors.

RESULTS: In the first year of operation, StudyLink made almost 700 referrals to studies at 27 research sites, and outreached to over 400 clinics, CBO's and ASO 's. Most patients who were referred had not previously been informed of opportunities to enroll in studies. Many clinicians had not previously considered referring patients to research protocols. After meeting together, research coordinators began to develop collaborative rather than competitive relationships among sites and to refer patients to each other if they were unable to enroll them into their own studies.

LESSONS LEARNED: A centralized database and single telephone source for information about clinical research can increase enrollment into clinical trials and expand access to a more diverse patient population.

PRESENTER CONTACT INFORMATION

Name: Ms. Ayisa Kennedy, Coordinator

Address: CDN-STUDYLINK

54 West 39th Street 11th Fl.

New York, NY 10018

Telephone: (212) 382-0699 ext.33

Fax: (212) 382-0669

E-mail: AYISAKENN@AOL.COM